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ABSTRACT

The author expresses concern about potentially damaging effects to mentally retarded persons from deinstitutionalization and normalization practices. Cited are the public's lack of awareness and the professionals' misplaced emphasis on researching the public attitude rather than improving the retardates' training. It is explained that there is a need to examine the impact of normalization and deinstitutionalization policies on the feelings and behavior of retarded persons. (CL)

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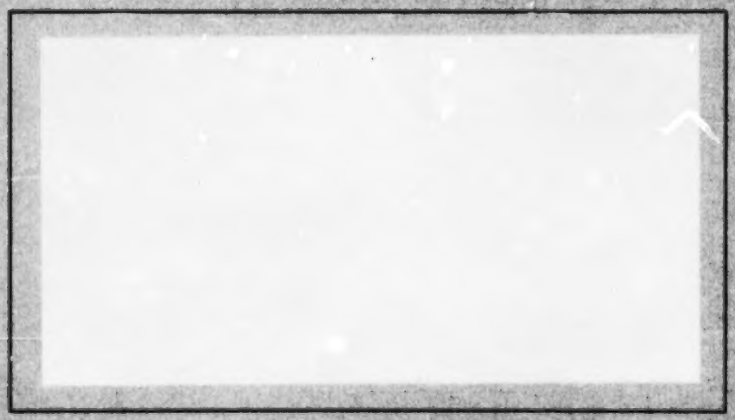

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Working Paper No. 81

SEVERAL ISSUES IN MENTAL RETARDATION: A NEEDED PERSPECTIVE?

Philip L. Browning

March 1, 1975

FOR BETTER OR FOR WORSE

I wish to take this time to thank you, Dr. Flanigan, and your staff for the invitation to participate in this annual event. I personally recognize the National Association for Retarded Citizens (NARC) as a most influential and respected organization. Over the years, it has represented the grass roots of commitment and dedication to the field of mental retardation. As a voluntary agency, it has been a front line advocate for those of less intelligence. Thus, I consider it an honor to be standing before you, state Executive Directors of NARC.

I would like to begin this morning by sharing with you an educational article carried in Time (1974) magazine. It stated that, instead of report cards, students in a metropolitan school district are bringing home an 8-1/2" x 14" number-filled sheet that looks more like a page from a company audit than a report card. To assist in school-home communication, parents are provided with a 32-page booklet and a 28-page manual with the title: Terminal Behavioral Objectives for Continuous Progression Modules in Early Childhood Education. As stated in the article, "Those brave or curious enough to look inside the manual find lists of anywhere from seven to twenty-three specific skills in thirty-nine 'modules' under seven basic 'curriculum areas'" (p. 59).

I trust that I don't have to share any more of the article with you in order to make my point: Although we do have the technology and methods available for us to assist mentally retarded persons in their efforts to live well in the world, too often, we become so microscopically enmeshed in innovations such as that just described that we lose sight of their relevance to the larger issue(s) at hand. For this reason, I have chosen to address you this morning on the philosophical forests rather than the technological trees. In so doing, I have generated a number of questions related to two areas. It will be your personal and professional responsibility to process individually your own answers.

Now to the first area of concern. As you know, much of the current action in the field of mental retardation is toward deinstitutionalization. Not long ago, I heard a gentleman in a state department indicate that their plans were to almost immediately empty the beds in the institution. We have been told by the federal people that it is of high priority. At our own Research and Training Center, we have been funded for a national survey on community live-in facilities for retarded persons. We know the President's Committee on Mental Retardation has set as one of its national goals the return of one-third of the retarded now living in institutions to community living.

No one agrees more than I with the desirability of deinstitutionalization. Yet, as I have sat and listened to many people who

are taking this movement to heart, I have seldom heard mention or the raising of any question that it may be for better or for worse.

My question is, are we ready, and are the retarded ready, for a mass exodus? If they return to the community and conditions are not in their favor for making it, will this not be another failure experience for them? Also, won't many of the unfortunate attitudes already held by the general public simply be reinforced? It is my opinion that we, as professionals and advocates, had better slow down in patting ourselves on the backs thinking we are leading the way to a more humane world for these people and ask ourselves, what is going to be necessary to make it work.

In order to assist mentally retarded persons in becoming integrated into our communities, do we need to better educate and prepare the public or better educate and prepare the retarded in order to successfully facilitate the exodus from institutions. A first and important step in seeking answers to these questions is to understand the normalization concept we are seeking to implement.

Let us compare the following two definitions of normalization which are probably the ones most widely accepted at this time. The first definition is Wolfensberger's (1972). Normalization to him is:

> Utilization of means which are as culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible (p. 78) (italics added).

This definition deals directly with the behaviors of persons who are

mentally retarded. The larger culture is to be used as a pattern, and possibly a prosthesis, for the persons who are to be normalized. However, this concept of normalization seems to ask little of the society at large in terms of its awareness and accommodation of deviance. On the other hand, it appears to require more of professionals and others concerned with the welfare of the retarded, for someone must assume the responsibility of preparing them for community life and monitoring their survival once there.

Normalization to Nirje (1969) is:

> . . . making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society (p. 181) (italics added).

This definition directs attention only minimally to the behaviors of the mentally subnormal themselves. Rather, emphasis is placed upon cultural accommodation to them. The public is expected to accept persons with intellectual disabilities, and this expectation is legislated in some areas. For example, certain percentages of occupants of privately owned housing have to be handicapped. Also, a set percentage of employees of businesses are, by law, to be handicapped. This is not to mandate that persons be placed in areas of life or work that are beyond their potential; rather, areas must be found to meet their unique set of competencies.

What should be our position? What approach should we emphasize in order to successfully achieve the goal of deinstitutionalization for many? Should the primary emphasis be upon retarded persons

and those concerned with their welfare to see to it that they accommodate themselves to society, or should we place the responsibility upon society to become more accommodating to deviant persons? Now let us move to the second area of concern, public awareness, which is intricately interwoven with these considerations.

In a society like ours, which places a high premium on man's cognitive and intellectual domain, the words idiot, feebleminded, mentally retarded, etc., still ring a note of public rejection in many. The retarded remain viewed by many as unfit to join our "educated" and "cultured" community of thinkers and achievers. For example, Roper Research Associates (1969), using the same sample used in predicting presidential elections, surveyed the attitudes of 1,500 American households toward the mentally retarded. They found that not only did more than half of the people surveyed feel that institutionalization was best for the mentally retarded, but also that only 16 percent of the respondents felt that the retarded should be permitted to work side by side with others. I wish to remind you that these are 1969 perceptions. What can we do to free retarded persons from the general public's outright misconceptions, prejudice and discrimination?

Certainly, all of us view increased public awareness of mental retardation as a necessary and essential goal. The President's Panel in 1962 devoted a specific section of its task report to this area. In addition, the President's Committee on Mental Retardation identified it as one of six major considerations by which they made

their 1972 recommendations. The truth is that vast amounts of time, effort, and money are being spent on bringing the mentally retarded into public awareness as a disability group. Ranging from Julie Eisenhower's one-minute spots on special education to nationwide coverage of the special olympics on ABC's Wide World of Sports, the emphasis appears to be on making known the existence and the humanity of the mentally retarded.

Because of our support, endorsement, encouragement and participation in achieving this goal, I am inclined to assume that we, more often than not, anticipate only positive effects from this effort. It will make things better; people will become more aware and understanding; improved conditions will result. However, I would like to suggest that increased public awareness via public media may be for "better" or for "worse," especially with respect to persons who are distant from the topic, people who are not in the field, those unacquainted with any mentally retarded person--in other words, the general public.

You know as well as I that they have not been sensitized to the term, mental retardation, as we have. Of course, we know that it is only a word, a concept, something that is both defined and imposed on certain people by us. I would suggest that this awareness is not the case with a large segment of our population. Only infrequently do they even come across the word. Nevertheless, you can be assured when they do, it triggers off their own "private" image of what it really means: Diseased, unable, incapable, brain damaged, totally

dependent, incurable, and so on. Unfortunately, increased awareness for these persons may be for worse.

I find it interesting that, in light of this, we as professionals still continue to lead the way in conducting more general public attitude studies on mental retardation than is done with any other disability group. As only one example, the Council for Exceptional Children recently published an extensive national study in a monograph entitled Public Awareness About Mental Retardation (Gottwald, 1970). Don't we already have a pretty good idea about what the general public's attitudes are? In what ways are the results of a public survey of attitudes going to alter our professional direction? Are we simply interested in verifying and reverifying what we already know? In attitude studies, do we not ask: What do you think the chances are of the mentally retarded making it? Do you think the mentally retarded can live a productive life? Do you think the mentally retarded . . . Do you think the mentally retarded . . . , etc., etc., etc.? Is not this perpetuating the conception many have that this is a homogeneous group? Do you know of any items on attitude scales that phrase the question: What do you think the chances are for persons who have the label mental retardation? Once the interviewees have responded, like, "I think most of them should be institutionalized," do we follow them up for the purpose of changing their thinking? Do we provide them with information which is incongruent with their idea of what mental retardation is?

Is one of our public awareness objectives in changing the public's attitude simply to make them more "tolerant" and thus accommodating of the condition of mental retardation? As an alternative, couldn't we place more emphasis on providing the retarded with training experiences which will prepare and enable them to deal with the public's intolerance? In a carefully instructed simulated learning environment, why not confront them with stigmatizing experiences through the process of desensitization and prepare them to "be ready" to cope with various types of prejudices which they will encounter from time to time? And why not teach them to be proud and assertive at the same time? I am not saying that the theme should be "mental retardation is beautiful." However, would not learning to say and believe, "I am beautiful," be a strong pillar for supporting the fullest benefits of normalization?

There is another matter which, though subtle, I find to be of importance. Shall we emphasize success or struggle? That is, when attempting to increase the public's awareness about these persons, should we emphasize their successes and then indicate how, with a little bit of public support and assistance, these and other successes might be enhanced? Or, should we emphasize the need for public assistance in order to make these successes possible? Both have the same goal; however, I find a subtle difference, and that difference may make the difference between for "better" or for "worse."

Wouldn't it be proper for us to consider the impact of these

public awareness efforts upon the persons most directly involved? We know that retarded persons themselves will go to great lengths to conceal the nature of their handicap from themselves as well as from others. Robert Edgerton (1967), in his study of patients released from an institution for the retarded, poignantly relates the reasons these people gave when asked why they had been institutionalized. They included epilepsy, promiscuity, mental illness, any of which are stigmatizing, but less damning to the individual than mental retardation.

Now, if I could share with you an example of this desire to shed an isolating label. The following is an excerpt from an actual counseling session with a "mildly" retarded adolescent girl in a residential setting. Unfortunately, I cannot recreate the affective nonverbal and paralinguistic (tone, pitch) behavior, which I so vividly remember with this client (Browning, 1974).

C I'm getting bored and want to go home because everybody is saying it's a mental retardation school. Every time Susie mentions it she just about scares me out of my pants. I don't want-to-go-to-be like that. I want to learn something. I don't want to be a mentally retarded child. (LONG PAUSE) We are all mentally retarded at sometime or another, aren't we? We all could be--a little bit--couldn't we? (LONG PAUSE) I don't know . . .

T (interrupting) Do you think you are retarded?

C Uh-uh. Not--well--a little bit I could because I can't study as well. Everybody has to be don't they?

T Would you think that in some ways you might be a slow learner?

C That's the truth. I'm a slow learner (p 245).

In conclusion, it is interesting to speculate on this issue of public awareness from the vantage point of the normalization philosophy. The question, from that frame of reference, is: How can we make the general public aware that there is nothing to be aware of? The question also arises of the efficacy of educating the public about the existence and humanity of a group, "the mentally retarded," when it is very likely that, whenever and however possible, individuals bearing the label will seek to lose it in the mainstream of society.

Unfortunately, time does not allow us to elaborate on many other issues which are now facing us. Simply let me remind you that it is only within recent years that we have made great strides in confronting the multiplicity of problems inherent in the field of mental retardation. Since the early 1960s, a comprehensive nationwide attack on the problem has been in motion. One of the more visible impacts during this era has been a proliferation of parental, civil, legal, professional and governmental advocates. These combined forces have helped lead to the current philosophy of normalization, the central thrust of which is for the retarded to enter the mainstream of society as much as possible. And this means that our work is just beginning, for better or for worse,

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